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Introduction

Recent molecular studies have identified two large genes, BRCA1 on chromosome 17 and BRCA2 on chromosome 13; mutations in these genes are now thought to be responsible for the majority of breast cancer cases in families with four or more affected relatives (Ford et al., 1995). Depending on the population studied, women with mutation in BRCA1/2 have 40% to 85% cumulative risk of developing breast cancer and 5% to 60% cumulative risk of developing ovarian cancer (Struewing et al., 1997; Whittemore et al., 1997; Schrag et al., 1997). There are several benefits associated with genetic testing for breast cancer susceptibility (Baum et al., 1997). For example, women found to be mutation carriers can increase the probability that breast cancer will be detected at early stage by increasing their breast cancer surveillance behavior and women who learn that they do not carry a cancer-predisposition mutation may experience relief and improvements in quality of life (Baum et al., 1997). However, genetic testing can also have adverse psychological consequences including loss of insurance, stigmatization, and increased psychological distress (Croyle et al., 1997; Bankowski et al., 1991, Holtzman, 1989). Most of the studies of the impact of counseling and genetic testing have predominantly focused on Caucasian women and have paid little attention to the role of ethnicity. Several line of research suggest that minority women may have different attitudes toward genetic testing and that they may react differently to notification of test results. For example, African-American women have less knowledge about cancer (Michieuet et al., 1982), they utilize screening methods for breast cancer less often (Vernon et al., 1991; Powell et al., 1990) and they have higher levels of cancer anxiety (Miller et at al., 1994). Furthermore, African-American women believe that they have less control over their health (Miller & Hailey, 1994), and they have been found to have strong fatalistic attitudes toward cancer and cancer treatment (Bloom et al., 1987). These findings suggest that African-American women may also differ in their attitudes about genetic testing. In order for genetic testing to be successfully implemented in this population, it is important to: 1) identify factors that predict interest in testing; 2) examine the impact of genetic counseling on interest in genetic testing: and 3) measure the impact of risk notification on psychological adjustment and screening behaviors.

The present study examines these issues among urban women of African descent. The aims of the study are to: 1) identify factors that are associated with interest in genetic testing. 2) demonstrate the psychological effects of genetic counseling for women with family history of breast cancer; 3) measure the impact of risk notification based on genetic testing and its effects on psychological functioning and preventive and early detection behaviors. To achieve these aims, three interrelated studies are being conducted. Study 1 is a cross-sectional study examining factors influencing interest in and readiness to undergo genetic testing. Study 2 is a longitudinal investigation of whether genetic counseling increases knowledge and promotes readiness to undergo genetic testing. Study 3 consists of pre- and post-notification evaluation of the psychosocial impact of DNA testing.

Body

Procedure:

African-American women scheduled for an appointment at the Breast Examination Center of Harlem (BECH) are being recruited. At the time of their visit the research assistant explains the study to eligible women and Survey 1 along with the consent form is mailed to interested women.

Once the women have completed Study 1, they become eligible for Study 2. Women who are at high risk for breast cancer are invited to receive individual genetic counseling and women who are at low risk for developing breast cancer are invited to participate in professionally-led group discussion. Women who express an interest in genetic testing after their counseling session are offered to donate a blood sample for BRCA testing. Approximately 2 weeks after their genetic counseling Survey 2 is mailed to the women. Participants who decide not to receive the genetic counseling are mailed copy of Survey 2 to complete at time points comparable to individual who undergo counseling.

Once the women have completed Study 2, they become eligible for Study 3. Subjects who elect to receive their test results are informed in accordance with IRB approved protocol (i.e., appropriate post-test counseling is provided). To assess acute distress and to monitor participants' well-being following notification, brief psychological measures are administered immediately after subjects notification session and again 10 days later. Follow-up surveys are mailed to all women approximately 1 (survey 3a), 6 (Survey 3b), and 12 (Survey 3c) months after their notification session.

Results:

To-date 145 women have been recruited for Study 1 but only 80 women signed the consent form. Forty-nine women have undergone genetic counseling (34 high risk women and 15 low risk women) and 30 women have donated blood for BRCA testing. As indicated in Statement of Work, for Year 1 and Year 2, we had anticipated that: 1) 170 women (57 high risk and 113 low risk) would be recruited; 2) 73 women (28 high risk, 45 low risk) would undergo genetic counseling; and 3) 25 women (14 high risk, 11 low risk) would donate blood for BRCA testing. However, as we encountered several problems during Year 1 of the study we have been unable to attain our goal. These obstacles which were described in detailed in the progress report for Year 1 included: 1) Not until May 1997 were we able to hire Ms. Duteau who is an African American genetic counselor. As Mr. Duteau had no prior training in cancer counseling she had to receive extensive training in cancer counseling at Memorial Sloan-Kettering before she was able to provide counseling to the women at BECH; 2) As the BECH does not offer free ovarian screening, recruitment was slowed down while we identified hospitals and clinics that provide ovarian screening at low or no cost; 3)The number of high risk women attending the BECH was lower than anticipated but has ben increased in Year 2 as we no have referrals from the Harlem

hospital; 4) The women recruited from the BECH were much less likely to return mailed questionnaires than has been our experience at other MSKCC clinics. This has improved since we now offer the women to complete the questionnaires with the research assistant either over the phone or in the clinic.

As we thought that it was important that we offered our women free BRCA2 testing we had an additional delay during Year 2 of the Study while we were negotiating BRCA2 testing with Myriad Diagnostic Services. As BRCA2 was cloned after the present study was funded we were only able to offer the women free BRCA1 testing. However, after negotiating with Myriad we are now able to provide the women free BRCA1 and BRCA2 testing.

Although recruitment has improved during Year 2 of the study it is highly unlikely that we will be able to attain our goal to recruit 600 women as we proposed in Statement of Work. As women who are at high risk for developing breast cancer due to their family history of the disease are most likely to benefit from genetic counseling and testing our main effort is now directed at attaining our goal of recruiting 200 high risk women.

Conclusions

To date 145 women have been recruited for Survey 1 but only 80 women signed the consent form. Forty-nine women have undergone genetic counseling (34 high risk women and 15 low risk women) and 30 women have donated blood for BRCA testing. We are behind in subjects recruitment, mainly due to unanticipated problems during the first year of the study. Although recruitment has improved we do not anticipate that we will be able to recruit 600 women as we had proposed. Our main goal is to recruit the proposed 200 high risk women as these women are most likely to benefit from genetic counseling and testing for breast cancer susceptibility. With the support from this award we have one paper submitted, one paper in press and one published abstract.

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Cancer-Specific Distress is Related to Women's Decisions to Undergo Brca1 Testing

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Problem
To examine the role of demographic variables, objective risk, perceived risk and cancer-specific distress in women's decisions to undergo genetic testing

Methods
One-hundred and five women with family histories of breast cancer completed a baseline questionnaire after which they were invited to attend a genetic counseling session and provide a blood sample for BRCA1 testing

Results
Fifty-five percent of the participants provided blood samples. After controlling for age, objective risk and perceived risk, which were positively related to provision of blood sample, women with moderate levels of cancer-specific distress were more likely to provide a blood sample than women with high or low levels of cancer-specific distress.

Conclusions
Cancer-specific distress affects women's decisions to undergo genetic testing for BRCA1. Genetic counseling needs to address cancer-specific distress, since it may increase the probability that individuals are making an informed decision about undergoing genetic testing for breast-cancer susceptibility.

Keywords: BRCA1, ~~Fear~~, Decision, Distress, Genetic testing

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INTRODUCTION

Consistent with risk estimates for most common cancers, women with histories of breast cancer in even one first-degree relative have been found in large epidemiological studies to be more than twice as likely to develop breast cancer themselves (1). A history of additional affected close relatives further increases the risk, as do other characteristics (e.g., bilateral disease, diagnosis at an early age) associated with a role for heredity in the etiology (2,3). Segregation analyses of families with multiple cases of breast and/or ovarian cancer suggest the existence of rare, autosomal dominant susceptibility genes (2,4). Linkage analyses has led to the identification and subsequent cloning of two large genes, BRCA1 on chromosome 17 and BRCA2 on chromosome 13; mutations in these genes are now thought to be responsible for the majority of breast cancer cases in families with four or more affected relatives (2). Depending on the population studied, women with mutation in BRCA1/2 have 40% to 85% cumulative risk of developing breast cancer and 5% to 60% cumulative risk of developing ovarian cancer (5–7).

For women with family histories, there are several benefits associated with genetic testing for breast cancer susceptibility (8). For example, women found to be mutation carriers can increase the probability that breast cancer will be detected at early stage by increasing their breast cancer surveillance behavior (e.g., mammography), or they can decrease the probability that breast cancer will develop by undergoing prophylactic mastectomy (9,10). In addition, women who learn that they do not carry a cancer-predisposition mutation may experience relief and improvements in quality of life (8). However, there are also several negative consequences associated with genetic testing (8). For example, women found to be mutation carriers may face uncertainty about their future, insurance discrimination, and worsened quality of life (11). Consequently, individuals considering genetic testing need to weigh the benefits against an array of possible costs of genetic testing. There are probably several factors that affect individuals' decision to undergo genetic testing. Intentions to undergo genetic testing for cancer susceptibility have been found to be related to younger age (12), higher education (12), and higher levels of perceived risk (13) and higher levels of cancer-specific distress, as assessed by the intrusion subscale of the Impact of Events Scale, IES (12,14). However, as intention to undergo genetic testing may not result in actual test (15) use, relatively little is known about predictors of actual test use. In two recent studies (16,17), variables found to be positively related to requests for BRCA1 test results included: being a female, younger age, more education, higher levels of objective risk, having health insurance, and higher levels of cancer-specific distress (IES). The participants in these studies were members of hereditary breast ovarian cancer (HBOC) families. They had provided blood samples several years earlier as part of studies conducted to localize the BRCA1 gene, and knew that a BRCA1 mutation had been identified in their family. Therefore, it is not clear if similar results would be obtained with individuals with less extensive family histories of breast cancer and no history of participation in genetic studies.

The possibility that cancer-specific distress may have a different impact on the decision to undergo genetic testing among women with less extensive family histories of cancer is raised by studies that have examined breast cancer screening behavior. These studies have found that high levels of psychological distress, assessed by a variety of measures, were related to reduced compliance with appropriate screening practices, including mammogprahy, clinical breast-examination, and breast self-examination (18–20). On the other hand, there have also been reports that high levels of distress about breast cancer facilitate appropriate screening practices (21,22). It has been suggested (23) that one of the reasons for these apparently contradictory findings is that the relation between distress and screening practices is curvilinear; too much or too little distress may inhibit screening while moderate levels of distress may facilitate screening.

The purpose of the present study was to examine the relation between demographic variables, objective risk, perceived risk, cancer specific-distress and decision making about BRCA1 testing among women

with family histories of breast cancer who had not previously received genetic counseling or participated in genetic studies. Based on the above reviewed literature we expected that education, objective risk, and perceived risk would be positively related to provision of a blood sample for BRCA1 testing. We also expected that women with moderate levels of cancer-specific distress would be more likely to provide a blood sample for BRCA1 testing than women with low or high levels of cancer-specific distress.

METHODS

Subjects

Participants were 105 women who were participating in an ongoing longitudinal study examining the psychological and behavioral impact of genetic counseling and testing for breast cancer susceptibility. The women were recruited from two clinics at Memorial Sloan-Kettering Cancer Center, the Special Surveillance Breast Program (~~SSBP~~ N=62) and the Clinical Genetics Service (~~CGS~~, N= 43). To be eligible for the study the women had to: 1) be 18 years of age or older; 2) have at least one first-degree relative diagnosed with breast cancer; 3) have no personal history of cancer; 4) have never undergone genetic counseling for breast cancer; 5) be able to read and write English; and 6) willing to provide informed consent.

Procedure

Women who were scheduled for a routine mammography at a special surveillance breast clinic or self-referred for genetic counseling were contacted by telephone approximately one to two weeks prior to their scheduled appointment. The study was described as an investigation to learn more about women's attitudes and feelings about breast cancer and genetic testing for breast cancer susceptibility. Participants were told that they would be asked to complete questionnaires several times over the course of the study and that they would have the opportunity to undergo genetic testing, free of charge to determine whether or not they carry a mutation in the BRCA1 gene. It was emphasized to the women that they could: 1) refuse to participate; 2) discontinue their participation at any time; 3) fill out the questionnaires without going for genetic counseling or genetic testing; 4) attend the counseling session without undergoing genetic testing; and 5) decide not to learn their mutation status once their test results were available. It was also emphasized that the women could not undergo genetic testing unless they had attended the counseling session.

Women who met the study criteria and were interested in participating were mailed a consent form, the baseline questionnaire package, and a pre-stamped envelope. A few days later the women were contacted again by telephone to verify that they had received the questionnaire package, review the consent form, and answer any questions that they might have. The women then returned the signed consent form and the completed questionnaires prior to their genetic counseling visit (see below).

Women at relatively high risk (relative risk ≥ 2) for breast cancer who had signed the consent form and returned the completed questionnaires were invited to come in for individual genetic counseling. The counseling sessions were conducted by a genetic counselor and lasted one to two hours. After construction of the pedigree, the following issues were addressed: 1) possible reasons for familial clusterings of cancer; 2) the likelihood of the occurrence of cancer in the pedigree to be hereditary (i.e. conforming to the criteria for a hereditary cancer syndrome) or familial (i.e. not meeting those criteria); 3) limitations of pedigree analysis, including the inability to distinguish between a sporadic and inherited cancer; 4) the relative importance of various risk factors other than family history; 5) risk estimates for developing cancer based on family history and/or associated with BRCA mutations; 6) options for prevention and early detection, and their limitations 5) limitations and benefits of genetic testing for BRCA1; and 6) risks of receiving test results, including insurance discrimination and adverse psychological consequences.

After the genetic counseling, subjects were given the opportunity to provide a blood sample to be tested for mutation in BRCA1. For subjects who decided to undergo genetic testing, a separate informed consent for DNA testing was reviewed and participants were urged to consider the impact of negative, positive, and ambiguous results. It was also stressed that participants could decide not to learn their results once they became available.

Women at relatively low risk for breast cancer (relative risk < 2.0) followed the same procedure as the women at relatively high risk, except they were invited to attend a group genetic counseling session which addressed the same issues as the individual counseling.

Measures

Demographic questionnaires

Age, education, race/ethnicity and marital status were assessed using a standard self-report form (24).

Family history questionnaire

This questionnaire is designed to assess the occurrence of cancer in participants' biological first- and second-degree relatives. Participants are asked to supply detailed information about their family histories of cancer, e.g., ages of onset and occurrence of multiple cancers. The data from this questionnaire was used by one of us (KB), a genetic counselor kept blind to all other study data, to estimate lifetime objective breast cancer risk.

Perceived risk of breast cancer

Following previously published methods (24–26), subjects rated on a scale from 0% (not at all likely) to 100% (extremely likely) their perceived likelihood of developing breast cancer in their lifetime.

Impact of Event Scale (IES) (27)

The intrusion subscale of the IES was used to assess breast cancer-specific distress. This seven-item subscale assesses frequency of intrusive thoughts about a specific stressor, in this case, the threat of breast cancer. The coefficient alpha in the present sample was .88, consistent with values reported by Horowitz et al., (27). Subjects indicated how frequently each thought or behavior occurred "during the past week including today". This measure was selected as Lerman, Schwartz et al (17) found that intrusive thoughts about breast cancer were related to BRCA1 test use.

RESULTS

Characteristics of the study population.

The mean age of the sample was 45. 1 years (SD=9.3; range 21 – 72), The majority of the women were white (91%), well educated (75% had attended college) and married (61%). The mean perceived risk was 59.2% (SD=26.5; range 0–100) and the mean objective risk was 28.5% (SD=13.3; range 11%-50%). For the cancer-specific distress measure, the mean score on the IES intrusion subscale was 6.3 (SD=7.5; range 0–31). Fifty-five percent of the participants (N=58) provided a blood sample for genetic testing.

Are sociodemographic variables, objective risk and perceived risk related to who provides a blood sample for genetic testing?

To determine the bivariate correlates of blood provision we conducted a series of χ^2analyses. Specifically, we evaluated the associations of sociodemographics, objective risk, and perceived risk with blood provision. Because the distribution for both perceived risk and objective risk was skewed these variables were dichotomized based on a median split. Following the procedure by Lerman and colleagues, (17) age was dichotomized as < 50 vs. ≥ 50 years.

As shown in Table I, older women tended to be more likely to provide a blood sample for genetic testing. χ^2 (1, N=105)=3.4, p = .06, and women with higher levels of perceived and objective risk were significantly more likely to provide a blood sample for

genetic testing ($\chi^2(1,N=105)=4.2$, $p=.04$; $\chi^2(1,N=105)=8.0$, $p=.005$ respectively).

TABLE I Bivariate Associations With Provision of a Blood Sample for BRCA1 Testing

Variable	*Reference group*	*% providing blood*
Age	< 50	49+
	≥ 50	69
Education	< College	57
	≥ College	55
Marital status	Married	59
	Unmarried	50
% objective risk	< 40	43**
	≥ 40	71
% perceived risk	< 70	48
	≥ 70	68*
Cancer-specific distress	Low distress	52**
	Moderate distress	77
	High distress	38

+p < .10 *p < .05 **p < .01

Is cancer specific distress related to who provides a blood sample for genetic testing?

We also evaluated the bivariate association between cancer-specific distress, as measured by the IES intrusion subscale, and the provision of a blood sample for genetic testing. In order to examine the hypothesized curvilinear relationship between distress and provision of a blood sample, we categorized scores into low distress (IES 0–1, N=46), moderate distress (IES 2–9, N=30), and high distress (IES 10+, N=29), following the cutoff points established by Lerman and colleagues (15). As shown in Table I, women with moderate distress scores were more likely to provide a blood sample than women with low or high distress scores (χ^2 (1, N=105) = 9.25, p = .01).

Is cancer-specific distress related to who provides a blood sample after controlling for demographic and risk variables?

To determine whether cancer-specific distress predicted blood sample provision after controlling for potential confounders, we conducted a logistic regression analysis with hierarchical variable entry. On the first step we entered all of the variables with significant ($p < .10$) associations with blood sample provision (age, perceived risk, objective risk). On the second step, we entered cancer-specific distress which was dummy coded with moderate distress serving as the reference cell. The results of this analysis are displayed in Table II.

TABLE II Hierarchical Logistic Regression Predicting Provision of a Blood Sample for BRCA1 Testing

Step and variables	*Reference group*	χ^2	*Odds ratio*	*95% CI*
Step 1				
Age	< 50 ≥ 50	14.9	2.4+	6.1, 0.98
objective risk	< 40 ≥ 40		3.1**	7.3, 1.32
perceived risk	< 70 ≥ 70		2.1+	5.2, 0.99
Step 2				
Cancer-specific distress	Low distress High distress	13.3*	.24** .11*	0.54, 0.11 0.42, 0.03

Note CI–Confidence Interval
+p < .10, *p < .01, **p < .001.

Age, perceived risk and objective risk, taken together, significantly predicted blood sample provision (χ^2 change (3, N=105) = 14.9, p = .002). Cancer-specific distress, entered on step 2, added significantly to the prediction of blood provision (χ^2 Change (2, N=105) = 13.32, p <.01). Inspection of the final odds ratios supported our prediction of a curvilinear relationship between distress and blood provision. Specifically, women with low levels of cancer-specific distress were less likely to provide a blood sample compared to women with moderate levels of cancer-specific distress (OR=.24, 95% CI=0.5, 0.1). Similarly, women with high levels of cancer-specific distress were less likely than those with moderate levels of distress to provide a blood sample (OR=.11, 95% CI=0.4, 0.03). In addition to cancer-specific distress, objective risk and perceived risk also were independently associated with blood provision (OR=4.4, 95% CI=18.5, 2.7; OR=2.5, 95% CI=6.7, 2.7 respectively). Specifically, women with higher levels of objective risk were about four times more likely to provide blood for genetic testing than women with lower levels of objective risk. In addition, there was a trend suggesting that women with higher levels of perceived risk were more likely to donate blood for genetic testing than women with lower levels of perceived risk.

DISCUSSION

The results of the present study indicate that cancer-specific distress is related to women's decisions to donate blood for BRCA1 testing. Women with moderate levels of cancer specific distress were more likely to donate blood than women with high or low levels of cancer specific distress. These results were obtained after controlling for age, objective risk and perceived risk, which were all positively related to provision of a blood sample for genetic testing.

The finding of a curvilinear relationship between cancer-specific distress and provision of a blood sample for BRCA1 testing is inconsistent with the finding reported by Lerman and colleagues (17) that individuals with high levels of cancer-specific distress were more likely to request BRCA1 test results than individuals with moderate or low levels of cancer-specific distress. There are at least three possible explanations for these discrepant findings. First, unlike the subjects in the present study, the participants in the study by Lerman et al. (17) included both affected and unaffected male and female members of previously studied HBOC families having extensive histories of breast cancer. Also, unlike participants in the present study who donated blood at the time of the study to learn their mutation status, the members of these HBOC families had donated blood several years earlier as a part of an investigation to localize the BRCA1 gene. Moreover, unlike participants in the present study, the members of the HBOC families were aware that a BRCA1 mutation had been found in their family. It is therefore possible that cancer-specific distress plays a different role in the decision to undergo genetic testing among members of these well-studied high risk families than among individuals in the present study who came from families with much less extensive family histories of breast cancer and who did not know if there was a BRCA1 mutation in their family. Second, cancer-specific distress may differentially affect the decision to provide a blood sample for genetic testing versus the decision to request test results. However, this is an unlikely explanation, as BRCA1 test results are now available for 34 of our participants, and none of them have declined to learn their mutation status. Third, the participants in these two studies could have had different levels of cancer-specific distress (IES). However, this is an unlikely explanation because the cancer-specific distress levels among participants in the present study showed a similar distribution (M=6.3, SD=7.5) to that reported by Lerman and colleagues (17) (M=6.2, SD=6.7). The finding in the present study that older women were more likely to provide a blood sample for genetic testing than younger women is also inconsistent with Lerman and colleagues (17) finding that younger women were more likely to request their BRCA1 test results. As with cancer-specific distress, these discrepant results may be due to the fact that the subjects in the present study differed on several variables from the participants in Lerman and colleagues

(17) study. Additional studies are needed to confirm the possibility that psychosocial variables (e.g., cancer-specific distress), as well as demographic variables (e.g., age), may differentially effect the decision to undergo genetic testing depending upon the population studied.

Whether the relationship between distress levels and the decision to undergo testing is linear or curvilinear, the results of the present study support an emerging consensus that distress may be an important variable to consider as we try to understand individuals' decisions to undergo testing. The data reported here revealed a significant relationship between cancer-specific distress levels and testing decisions even after controlling for other previously published predictors (e.g., age, objective risk, perceived risk). Cancer-specific distress has also been found to affect the effectiveness of genetic counseling. Lerman and colleagues (26) found that women who had high levels of cancer-specific distress were more likely to continue to overestimate their lifetime risk of developing breast cancer after the risk counseling than women with low levels of cancer-specific distress. In addition, cancer-specific distress may play a role in the notification of BRCA1 test results as suggested by a recent study (28) which found that individuals with mutation in the BRCA1 gene reported significantly higher levels of cancer-specific distress than individuals found to be noncarriers. Take together, the results from these studies and the present study suggest that cancer-specific distress needs to be addressed in the context of genetic testing. Understanding the role of cancer specific-distress in genetic testing will assist in designing interventions which will increase the probability that individuals are making an informed decision about undergoing genetic testing for breast cancer susceptibility and minimize the possible negative psychological impact of genetic testing.

Consistent with previous studies which found that intentions to undergo genetic testing were related to high levels of perceived risk (13,14) the present study found that women with high levels of perceived risk were more likely to provide a blood sample for genetic testing. This finding further indicates the importance of addressing cancer-specific distress, as genetic counseling may not be effective in improving risk comprehension among women with high levels of cancer-specific distress (26).

The results of the present study should be interpreted cautiously for several reasons. First, as a majority of the women were White and well educated, we can not generalize our findings to individuals from other ethnic and sociodemographic backgrounds. Second, because of the small sample size we could not examine in the logistic regression analyses whether the relation between cancer-specific distress and provision of blood sample differed between women who were recruited from a special surveillance breast program and women who were self-referred for genetic counseling. However, the results form the bivariate analyses, computed separately for each recruitment site, indicated that, at both recruitment sites, women with moderate levels of cancer-specific distress were more likely to provide blood samples than women with low or high levels of cancer-specific distress. Third, the generalizability of these findings to BRCA2 test use needs to be examined as the BRCA2 gene had not been cloned when the present study started.

Despite these limitations, the results of the present study indicate the importance of understanding the role of cancer specific-distress in women's decisions to undergo genetic testing for breast cancer susceptibility.

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SYM 2B

GENETIC COUNSELING AND TESTING FOR BREAST CANCER SUSCEPTIBILITY AMONG WOMEN WITH FAMILY HISTORIES OF BREAST CANCER

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Genetic counseling is important for women who are considering genetic testing for breast cancer susceptibility. However, to date, relatively little is known about the impact of individualized genetic counseling on: perceived risk for breast cancer susceptibility, emotional distress (general and cancer specific) and decision making about genetic testing. In an ongoing study we are examining these issues among women with at least two first degree relatives with breast cancer. Two weeks prior to the counseling session and 2 weeks after the counseling session the women completed measures of: general distress (Brief Symptom Inventory); cancer specific distress (Impact of Event Scale); readiness to undergo genetic testing; and perceived risk for breast cancer susceptibility. In addition, after the counseling, the women are offered the opportunity to undergo free genetic testing. Preliminary results indicate that the genetic counseling is effective in reducing perceived risk for breast cancer to levels consistent with empiric genetic risk, and in reducing cancer-specific distress. No change was seen in general distress. Prior to the counseling 60% of the women indicated that they were ready to undergo genetic testing and 40% indicated that they were not yet ready. After the counseling 66% of the women who had indicated that they were ready underwent genetic testing and 35% of the women who had indicated that they were not yet ready underwent genetic testing. These results suggest that individualized genetic counseling may play an important role in women's decision making regarding genetic testing. The impact of positive and negative test results on perceived risk and distress will also be discussed.

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Psychological distress and breast self-examination among Black women with different family histories of breast cancer

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Abstract

Studies demonstrating that women with family histories of breast cancer overestimate their personal risk and have high levels of psychological distress that affect their breast cancer screening behaviors have used primarily White samples. We compared Black women with at least one first-degree relative of breast cancer (Risk Group N=23) to Black women without a first-degree relative with breast cancer (Comparison Group, N=32) on measures of psychological distress and breast self-examination (BSE). The Risk Group were more likely to have a high perception of perception of personal risk of developing breast cancer (chi-square = 4.96, $p < .026$) and higher intrusive thoughts about breast cancer ($p < .024$) than women in the Comparison Group. Across Groups, we found that women with a high perception of risk and more intrusive thoughts were less likely to perform BSE at the recommended monthly interval; they either under- or over-performed BSE (chi-square 11.556 $p < .003$). This study confirms previous research demonstrating higher levels of psychological distress among women at familial risk for breast cancer and extends the research to demonstrate its potential impact on BSE among a minority group who have an elevated risk of dying from breast cancer.

Introduction.

Breast cancer is the second leading cause of cancer death in American women Estimates suggest that more than 180,000 new cases of breast cancer were diagnosed in 1997 and more than 43,000 women died of the disease (1). In the Black community, breast cancer has had a substantial impact. A consistent finding has been that, although Black women are diagnosed with breast cancer slightly less often than White women, the five-year survival rate is significantly lower for Black women (80% for White women versus only 64% for Black women) (2). For both Black and White women having a family history of breast cancer is a risk factor for developing the disease (3). Consequently, Black women with family histories of breast cancer may face the combined threat of being at an increased risk of dying of breast cancer than women in the general population and of being more likely to die from the disease than their White counterparts.

The psychological consequences of having a family history of breast cancer, and its impact on breast cancer screening has not been well-explored in Black women. It is particularly important to understand how having a family history of breast cancer may affect psychological distress and surveillance behavior in these women as they are at highest risk for developing the disease themselves. In this paper we examine how having a family history of breast cancer relates to psychological distress and breast self-examination among Black women.

Association between psychological/cognitive factors and family history

Similar to White women, the strongest predictor of a Black woman's lifetime risk of developing breast cancer is having a family history of the disease (4). The greatest risk is to

women with multiple affected close relatives, suggesting the presence of a mutation in one of the primary breast cancer susceptibility genes (e.g., BRCA1, BRCA2), but even having a single first degree relative with breast cancer can increase risk (5). Accumulating evidence suggests that women with family histories of breast cancer overestimate their risk and may have high levels of distress (e.g., 6-9). Kash et al. (1992) found that 27% of women with family histories of breast cancer experience clinically significant psychological distress. High levels of distress among women with first degree relatives with breast cancer were also reported by Lerman and colleagues (1993), who found that 53% of these women experienced intrusive thoughts about breast cancer (10). Two recent studies that have included concurrent assessments of a comparison group drawn from the community have confirmed that perceived cancer risk and distress levels are higher among women with family histories of breast cancer (8-9).

To date, psychological and cognitive factors in studies of women with family histories of breast cancer has largely been based on samples of White women. Initial findings in samples of Black women with family histories of breast cancer suggest that, like White women, they perceive themselves to be at higher risk for developing the disease (11). In a study of 60 African-American, low-income women with family histories of breast cancer, the majority (55%) perceived themselves to be at risk for developing breast cancer and half reported being at least somewhat concerned about their chances of developing breast cancer (12). Bowen also found that Black women exhibited particularly high levels of perceived risk for breast cancer (13). When Black women with family histories of breast cancer were compared to their White counterparts, Hughes and colleagues (1996) found that Black women: 1) exhibited significantly

greater concerns about their personal risk of breast cancer and worries about their affected relative; and, 2) had higher cancer-specific distress (14).

Distress and breast self-examination

Psychological distress among women with family histories of breast cancer is not only clinically significant in its own right, it may also have an impact on breast cancer screening behaviors. Kash and colleagues (1992) found that higher levels of cancer-specific distress among women at familial risk to be related to poor compliance with clinical breast examinations, as well as poor compliance with recommended monthly breast self-examination (BSE) (6). Similarly, Benedict and colleagues (1997) found a significant inverse relationship between fear of breast cancer and frequency of breast self-examination among daughters of women diagnosed with breast cancer (15).

BSE over-performance has also been linked to higher psychological distress. Lerman and colleagues (1994) found that higher levels of psychological distress among women with family histories of breast cancer was associated with both insufficient and excessive breast self-examination behavior (> once a month) (7). A more recent investigation of predictors of BSE over-performance among women at familial risk (16) found that African-American women were over-represented in the group of women who over-performed BSE, and that over-performers were more likely to frequently think about breast cancer. Similarly, Royak-Schaler et al., (1995) found that perception of risk was related to breast cancer screening practices for African-American women under 50 years old; they were the most likely to have obtained a CBE and mammogram (12).

To our knowledge, the present study is the first to compare Black women with family histories of breast cancer to those without family histories of breast cancer on perceived risk, psychological distress and compliance with breast self-examination guidelines. The inclusion of a comparison group without breast cancer in first-degree relatives provides an important benchmark against which to assess both cancer-specific and general distress as well as BSE frequency. Most studies which have found that psychological distress and intrusive thoughts about breast cancer relate to inappropriate breast self-examination did not include a comparison group making it impossible to examine family history related differences in distress and BSE. Since the media has recently focused so much attention on breast cancer awareness it may be that women without a family histories of breast cancer also experience distress and intrusive thoughts about breast cancer which may be sufficient to impact on proper breast self-examination. Based on the literature reviewed above, we hypothesized that Black women with family histories of breast cancer would score higher on measures of distress than Black women without family histories of breast cancer and that psychological distress would predict poor compliance with recommended breast self-examination guidelines.

Method

Participants

Black women with (Risk Group, N=23) and without (Comparison Group, N=32) family histories of breast cancer were recruited for the present study. Women in the Risk Group had at least one first-degree relative with breast cancer. Women in the Comparison Group had no first-degree relatives with breast cancer. Women were excluded if they: 1) were unable to speak or

read English; 2) were less than 25 years old; 3) were unable to give meaningful informed consent; 4) had a history of neoplasm of an abnormal pathologic report; 5) were pregnant; 6) had evidence of abnormal results on their most recent mammogram.

Setting

All participants were recruited from an inner-city cancer screening center in New York City -- (The Breast Examination Center of Harlem; BECH, a community program of Memorial Sloan-Kettering Cancer Center). The BECH provides advanced, comprehensive diagnostic cervical and breast screening services to women of the Harlem community. All services (e.g., mammogram, pap smear, clinical breast exam) are provided at no out-of-pocket expense to the client. Women who attend the BECH are instructed in how to perform BSE and receive routine clinical breast exams at every screening visit.

Procedures

In person contact was made with the women at the breast clinic and the study was described. All data for this study were collected as part of a larger investigation of psychobiological factors associated with having a family history of breast cancer. Interested women were then scheduled to meet with study personnel at least one month after the initial contact, because we have previously documented high levels of acute distress on the day of mammography screening (8). At their scheduled appointment, participants were asked to read and sign the consent forms and were given standardized measures that included cognitive and psychological variables. Each woman took approximately 60-minutes to complete the questionnaires. As a consideration to participants, additional questionnaires that assessed breast

cancer screening behaviors and demographic data were given to participants to complete at home and return in a pre-paid mailer the next day (see Measures below). All participants were offered $20 plus the cost of public transportation to and from the study site.

Measures

Demographic and medical questionnaire. A standard questionnaire was used to obtain information on age, race/ethnicity, education, marital status, employment, smoking, height, weight, and other health-related variables (9). Histories of cancer in the family were obtained using a self-report form (9,17).

General distress

Brief Symptom Inventory (BSI) (18). The BSI, a validated and highly reliable brief form of the classic SCL-90 (Symptom Checklist-90 revised), was used to provide an assessment of general distress over the past three weeks. The BSI has nine symptom dimensions and three global indices of stress symptomatology. To reduce the likelihood of type I error, only the General Severity Index (GSI) was analyzed for the current study. Because preliminary analyses indicated that scores on this index were not normally distributed, results were dichotomized (median split, .396) and subsequently analyzed with a non-parametric test (X^2).

Cancer-specific distress

Impact of Events Scale (IES) (19). The IES is a 15-item self-report inventory that assesses intrusive thoughts and avoidance. The scale items are anchored to a specific stressor (in this case, the threat of breast cancer) and yield subscores for intrusive and avoidance experience. This measure was chosen because it assesses symptoms reflective of current distress (19), and

because in studies of predominantly White samples it has revealed differences in cancer-specific distress between women with and without family histories of breast cancer (e.g., 8-9). The measure has also been used with Black women with family histories of breast cancer (14). Subjects were asked to rate how frequently each thought or behavior occurred during the past three weeks. Of particular interest in the present study was the intrusive thoughts subscale, as Lerman et al., (1993) have previously reported that women with family histories of breast cancer score especially high on this measure. Scores were not normally distributed and were dichotomized at the median (median split .396, T-score=54).

Perception of breast cancer risk

Perceived risk for cancer. Perceived risk for cancer was assessed by asking subjects to rate their perceived likelihood of developing breast cancer in their lifetime from 0% (not at all likely) to 100% (extremely likely) (8). Because preliminary analyses indicated that the data on this measure were not normally distributed, with approximately half the participants indicating that they were at 50% or greater risk, results were dichotomized (less than <50% lifetime risk and 50% or more lifetime risk).

Breast self-examination behavior

Assessment of breast self-examination. Participants were asked to respond to the following question: *How often do you perform breast self-examination?* on a seven-item measure ranging from 1- more than once a month to 7 - never. For statistical purposes, the scale was broken down into three sections 1) more than once a month (over-performers); 2) once a month (appropriate performers); and, 3) less than once a month - (under-performers). Accuracy of self-

reported breast screening has been validated among sociodemographically low-income, minority and diverse women (20-21).

Results

Demographic variables for the Risk and Comparison Groups are shown in Table 1. No significant differences between the groups were found. Consistent with their family histories of breast cancer, the Risk Group had a significantly ($t=3.14$, $p \leq .004$) higher objective risk of breast cancer than the Comparison Group, as determined by the Claus model (3) (see Table 2).

As shown in Table 2, women in the Risk Group were more likely to report high perceived risk than women in the Comparison Group (chi-square = 4.96, $p < .026$). The Risk Group was also significantly more likely to report intrusive thoughts about breast cancer than the Comparison Group ($p < .024$). These results support that, like predominantly White samples, Black women with family histories of breast cancer are more likely to have intrusive thoughts about breast cancer than Black women without family histories of breast cancer. General distress (GSI) did not differ between the groups.

The Risk and Comparison Groups did not significantly differ in frequency of breast self-examination. As shown in Table 2, only about 20% of the women adhered to recommended guidelines. Therefore, we examined if perceived risk and psychological distress predicted BSE frequency across both groups of women.

Although there was no significant main effect for perception of risk or intrusive thoughts on BSE frequency, there was a significant interaction between these two variables (see Table 3). In further analyses to explore the source of the interaction (see Table 4), we found that Black

women with high perception of risk and more intrusive thoughts were less likely to perform BSE according to American Cancer Society guidelines. Having a high perception of risk and high intrusive thoughts predicted both BSE under- and over-performance (chi-square 11.556 $p < .003$). Among women with low perception of risk and no intrusive thoughts, no significant differences were found (chi-square 3.31 $p < .191$).

Discussion

This study sought to contribute to the literature in several ways. First, we examined the psychological impact of having a family history of breast cancer in a sample of African-American women through the inclusion of a comparison group without family histories of breast cancer recruited from the community. To our knowledge, this study is the first to utilize a comparison group in a solely Black sample to examine perceived risk, psychological distress and their relationship to breast self-examiniation behavior.

Second, we conducted concurrent assessments using standardized measures of cancer-specific distress, (IES), and general distress (GSI). Third, we recruited women from a facility that offers free breast and cervical cancer screening and provides written, video-taped and hands-on instruction in appropriate breast-self examination. In so doing, we sampled from a population that presumably knows how and when to perform BSE.

We found that Black women with family histories of breast cancer (Risk Group) were significantly more likely to have high perceptions of their breast cancer risk and higher levels of intrusive thoughts about breast cancer than those without a FDR with breast cancer. Unlike some previous studies with predominantly White participants (6,8), we did not find that having a family

history of breast cancer by itself was associated with greater general psychological distress.

The finding that the Risk Group had a higher perception of personal risk is consistent with previous findings (22-24), but we did not find that having a family history was associated with adherence to BSE screening guidelines. Our findings would seem to be at odds with those of Nemcek (1989) who reported that the experience of having a close family member or friend battle breast cancer encouraged BSE frequency among Black women. In that study, Black women who were "directly-exposed" to someone with breast cancer were significantly more likely to perform BSE than Black women who were not exposed to the disease (25). One might imagine that having a first-degree relative with breast cancer (as our Risk Group) "directly-exposes" a woman to breast cancer, but we did not directly assess such interactions in this study. Our findings are consistent with those of Alagna et al. (1987) in a study which compared women at high familial risk of breast cancer (five or more relatives with breast cancer), to women at low risk for breast cancer (no breast cancer in immediate family members) and found that high risk women were more knowledgeable about BSE, but did not significantly differ from the low risk group on BSE frequency (26). In that study, participants' race were not reported.

Our results should also be compared to those in the literature regarding the importance of perception of risk and intrusive thoughts on BSE frequency. Interestingly, in the present study it was the interaction of intrusive thoughts and perception of risk that predicted BSE across the Risk and Comparison Groups. We found that women with high perceptions of risk and high intrusive thoughts were less likely to adhere to BSE guidelines. They either under- or over-performed BSE. This finding is consistent with a study by Lerman et al. (1994) which found that

a subset of younger women with family histories of breast cancer were practicing BSE excessively, and this was related to intrusive thoughts about developing breast cancer. Levels of generalized psychological distress were highest among women who never practiced BSE or practiced less than once per month (7)

In light of cultural, social and economic differences between Black and White women, it will be important in future studies to examine such factors as contributors to the relationship between family history, psychological distress, perceived risk and BSE frequency. For example, it may be that having a family history of breast cancer psychologically impacts Black women differently than White women. Hughes et al (1996), found that Black women with a family history of breast cancer were significantly less likely than White women to report heightened perception of personal risk after their relative was diagnosed with breast cancer (61% versus 82%; $p < .001$). The Black women in that study also differed significantly from the White women in BSE frequency; the Black women were more likely to perform BSE excessively. It may be that Black women in general over-perform BSE. In our study, with an entirely Black sample, we found a high incidence of excessive BSE (43% of the Risk Group and 38% of the Comparison Group).

The importance of appropriate, monthly BSE should not be minimized for several reasons. First, BSE is a no-cost health behavior that may empower and motivate women to perform other cancer screening behaviors. For example, a recent study found that Black women who were under-screened or unscreened for mammography were twice as likely to be those who performed BSE infrequently or not at all (27). In another study, performing regular BSE was associated

with higher rates of mammography screening (28). And still a third study (29) found an association between monthly BSE and recency of Pap test. Second, Black women present with later-stage breast disease than White women (30). This finding is likely to be related to a host of variables including cultural and social barriers (30), but the major factor is though to be the lower socioeconomic status of Black women as a whole which makes access and quality care less available (31).

Third, there is evidence that performing certain components of BSE (visual examination of the breasts, palpation with finger pads, and examined breasts with three middle fingers) reduced the risk of dying from breast cancer (32). Although mammogram is the most frequent method of breast cancer discovery, BSE has been found to run a close second (33). Finally, according to Epstein, et al. (1997) over performance of BSE may increase the likelihood false-findings, with attendant high anxiety and reduced adherence to appropriate BSE.

Understanding BSE frequency among Black women may help explain why Blacks, who are less likely to develop breast cancer, have a lower five-year survival rate than Whites once diagnosed (34). Later stages at diagnosis and delay in seeking treatment once symptoms are present (35-36) appear to explain Black/White mortality differences. Low-income and minority women have been found to delay seeking treatment out of fear, marginal access to medical care, and procrastination (37). As it has been reported that women are more likely to seek help for potential breast cancer if they are BSE performers and users of mammograms (38) and because there is evidence which suggests that regular and proper BSE may reduce breast cancer mortality by 18% (39), it is important that Black women, particularly those with a family history of breast

cancer, utilize every defense available to them against breast cancer, including BSE. The present study is another step in understanding possible psychological barriers to compliance with BSE guidelines among Black women.

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Table 1. *Subject characteristics by Group*

	Groups	
	Family History Group	Comparison Group
Mean Age (SD)	45.29 (9.01)	44.71 (10.22)
Education (H.S. graduate)	90%	84%
Income (>$20,000)	56%	46%
Currently married	30%	29%

No significant group differences were found

Table 2. *Comparison of family history groups on psychological and behavioral measures*

	Groups	
	Family History Group	Comparison Group
Objective lifetime risk (Claus model)	17%	11%
Perception of risk		
50% or more lifetime risk	74%	43%
Less than 50% lifetime risk	26%	57%
Intrusive thoughts (sub-scale of IES)		
IES ≥ 1	65%	35%
IES = 0	35%	65%
General distress (GSI)		
Above GSI median[a]	52%	48%
Below GSI median[a]	43%	47%
Breast self-examination		
More than once a month	43%	38%
Once a month[b]	22%	25%
Less than once a month	35%	38%

[a]Median split .396 T-score = 54

[b]The American Cancer Society recommends that women over 20 should perform BSE once a month

Table 3. *Interaction of perceived of risk and intrusive thoughts to predict BSE frequency*

	DF	Chi-sqare	Prob.*
Perception of risk	2	4.61	.099
Intrusive thoughts	2	2.11	.348
Perception of risk x intrusive thoughts	2	7.01	**.030**

***Logistic regression analysis**

Table 4. *Intrusive thoughts (IES) about breast cancer predicted frequency of BSE among women who perceived themselves at high risk*

	Breast self-examination			
Perceived Risk	**Less than once a month**	**Once a month**	**More than a month**	
50% or more lifetime risk				
IES ≥ 1	**83%**	3%	**71%**	Chi-square 11.56
IES = 0	17%	**90%**	29%	**p < .003**
Less than 50% lifetime risk				
IES ≥ 1	23%	67%	57%	Chi-square 3.31
IES = 0	77%	33%	43%	p < .191